

“...little chunks of my life missing...”:

Memory, identity and rights in child social care records

By Victoria Hoyle, Elizabeth Shepherd and Elizabeth Lomas

“...it’s not just paper. You see, to them it’s just paper, words on paper, but to the person who’s reading it, who it’s about, it’s everything. It’s their life.” (Susan, Care Leaver)

Introduction

There are currently over 75,000 children and young people growing up ‘in care’ in the UK, living with foster parents or in residential homes (Department of Education & Office of National Statistics, 2018). Estimates suggest that up to 1% of the adult population – half a million people – have experienced out-of-home care as children. While individual experiences vary enormously, most care-experienced people share something in common: their childhoods have been intensively documented by social workers, health workers and carers. Local authorities, as ‘corporate parents’, have a legal responsibility to ensure that certain information is captured and preserved about each child in their care. This has been true, to a greater or lesser extent, since the Children Act 1948. Subsequently, a complex framework of legislation and regulation has set out what records should be created, when and by whom. Since 1989, records relating to children in care have been subject to a mandatory retention of 75 years, on the understanding that they are an important resource, not only for the accountability of the care provider, but for the care leaver who may want to access this information later in life.

Care leavers may be motivated to access their records for multiple reasons. They may wish to fill gaps in their memories or answer simple questions, such as why was I taken into care or where did I live. They may be seeking specific medical or personal information, or could be pursuing a legal case against abuse or neglect.

In these circumstances, they turn to the records created about them by care providers to reconstruct personal histories. Research suggests that thousands of these requests are made each year in England under the subject access provisions of data protection legislation (Goddard, Feast & Kirton, 2008). However, care leavers report multiple challenges in finding, accessing and understanding their records. Bureaucratic processes, heavy redaction, and a lack of support and aftercare leave many confused, frustrated, and traumatised.

MIRRA: Memory – Identity – Rights in Records – Access

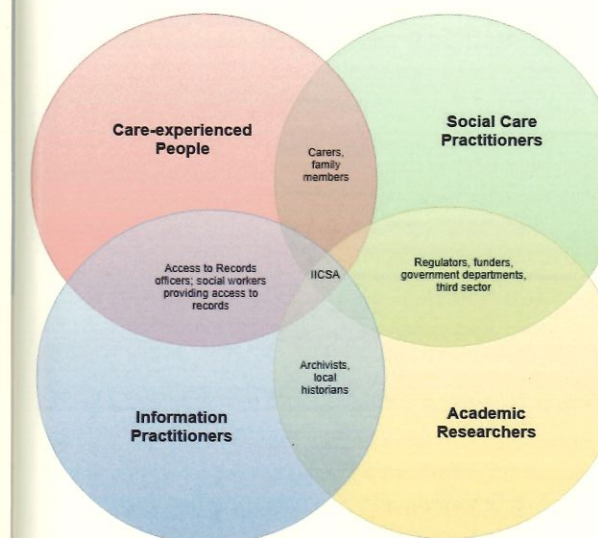
MIRRA, which stands for memory – identity – rights in records – access, is a participatory research project based in the Department of Information Studies at UCL, conducted in partnership with The Care Leavers’ Association. Over the last 2 years, four academic researchers and six care-experienced adults have explored the needs, experiences and rights of care leavers who seek access to their records. We took a ‘recordkeeping approach’ to the study, thinking not only about access, but about how records are created, understood, used and managed throughout their existence. This approach acknowledges that the capacity of records to support a person’s memory and identity needs is contingent on a number of factors, beginning with what is captured in the first place.

Between October 2017 and October 2019, we collected data during interviews, focus groups and workshops with over 80 representatives from four key stakeholder groups. These were:

- the social work practitioners, who create and use records;
- the information professionals, who manage records;

- the academic researchers, who wish to study records;
- and, most importantly, the children, young people and care leavers that the records are about.

Each of these groups has different, and sometimes competing, recordkeeping needs. In between and overlapping are other stakeholders, who emerged during the project, including carers and family members; regulators; funders; government departments and IICSA, the current Independent Inquiry into Child Sexual Abuse in the UK.



MIRRA research participants, © UCL.

We examined two key research areas. Firstly, we looked at issues surrounding access to records for care-experienced people, including questions about redaction and the provision of associated services and support. Secondly, we interrogated recordkeeping practices, including the language and content of records as they had been written, records management procedures, digital systems and the memory and identity work that is done while someone is in care.

Analysis of the data highlighted three interconnected findings. Firstly, there was evidence of poor or inadequate records management across the child social care field. Secondly, the research underlined care leavers’ negative and traumatic

experiences of accessing their records, focused particularly around redaction. In contrast, when the recordkeeping and access was done well, it was transformative. Thirdly, problems were seen to be rooted in a complex and fragmented legislative framework that made it difficult for care leavers to exercise their rights and for recordkeepers to fulfil their responsibilities. These findings have significant implications for both the management of child social care records and the provision of subject access.

Poor records management in child social care

Recordkeeping issues often first arose at the point of creation or ‘non-creation’. Cultures of recording in social work, including the use of unexplained shorthand or acronyms, prejudicial or euphemistic language and incomplete records, make it difficult to retrieve authentic and trustworthy information. In many cases, records are assumed to have been lost or destroyed, with no auditable account of what had happened to them. This is no doubt, in part, because records management has been a low priority across the child social care sector. As a result, many public, voluntary and private organisations have large bodies of paper and digital records over which they have very little or no physical and intellectual control. Standards are highly variable.

In terms of physical control, organisations are often unsure of where records are stored, their state of preservation and the security conditions. This is true of both paper and digital records and is compounded in the latter case by frequent changes to IT infrastructure. Less than 20 years after the widespread adoption of digital case management systems, many records are ‘stuck’ in inaccessible legacy programmes or cannot be opened in original formats.

In terms of intellectual control, few organisations have catalogues and indexes of records which are sufficient to locate specific material, nor do they know when, how and why records have been created, or how decisions about them have been made. This is coupled with poor institutional memory regarding former practices, both in terms of safeguarding and recordkeeping, especially where organisations have merged, changed

jurisdiction or ceased to operate. Organisations rarely have arrangements in place for archiving, either for individual use or public benefit. The introduction of digital systems has often been seen as a long-term solution to the problems of findability and long-term accessibility, but without proper consideration for digital preservation.

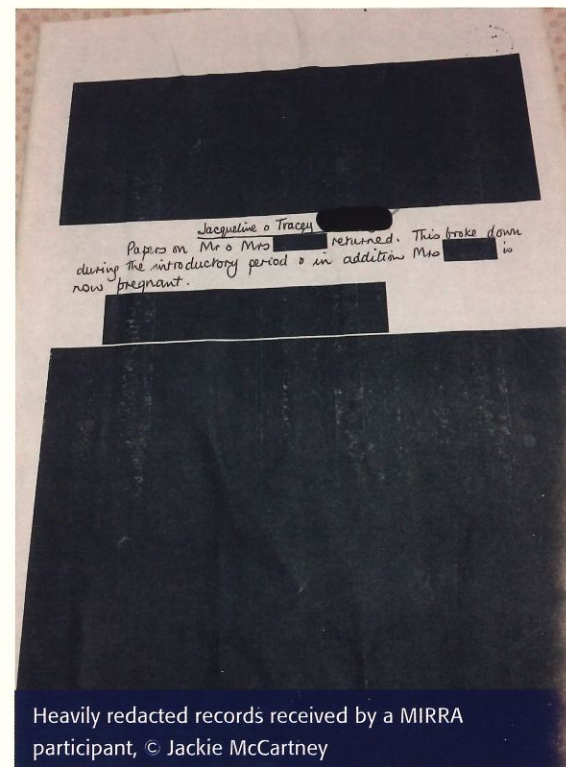
There are additional complications. Increasingly, records relating to services to children in care are created and maintained by commissioned organisations, often without clear contractual obligations to manage records in the long-term. Further, while multi-agency working has helped to facilitate information sharing, it has also vastly increased the potential for duplication, error and omission in records held across multiple information management systems. This poor records management not only puts organisational assets at risk, but also impacts on people's ability to locate information about themselves.

Problematic and traumatic access to records processes

Our research found that subject access requests for care records were fraught with difficulty for everyone involved. Care leavers are often confronted with bureaucratic, dehumanising processes that are difficult to understand, while social workers and recordkeepers have heavy workloads and dwindling resources with which to manage requests. The lack of organisational records management already described means that simply identifying where and to whom to direct an access request is confusing; finding the records at the other end equally so. There is often a long wait for receipt of the response, and in a significant number of cases nothing may survive or be located.

When requests are fulfilled, records have often been heavily censored through redaction. Third-party information is stripped out, sometimes indiscriminately without consideration of the impact on the recipient. As care records are, by their nature, full of third parties, including a person's siblings, parents, family members, friends and carers, this can leave a person confronting pages and pages of blacked out text.

Very little information is provided to explain what redaction is or how to appeal decisions, leaving recipients feeling powerless and dehumanised.



Heavily redacted records received by a MIRRA participant, © Jackie McCartney

Our research strongly indicates that what and how much third-party information to redact is the main area of tension and challenge. This was true from both the perspective of the care leaver who made the request and the staff tasked with making decisions about disclosure. For the care leaver, redaction often appeared random and nonsensical, whereas for the staff it was a psychological burden that was also resource intensive. The disclosure or redaction of third-party information requires the practitioner managing the request to use their judgement to determine what is reasonable, taking into account the rights of that person to privacy and confidentiality. Where the third party is a sibling, parent or carer, whom the subject will probably know, and whose information may be critical to understanding what happened to them, then choosing to redact can have negative emotional impacts.

The use of discretion in the disclosure of third-party information under the subject access provision of the Data Protection Act and the GDPR



Visual minutes from a research meeting in Manchester, showing the themes of the MIRRA project, © UCL

is apparently not consistently applied or sufficiently understood. Our research has found that, in many instances, the removed information could have been provided under data protection law, but the redactor had not properly considered the rights and existing knowledge of the recipient. For example, many people processing access requests were unaware of critical case law, such as *Gaskin v UK 1980* (decided EU CHR 1989), in which the European Court determined that **Graham Gaskin**, a victim of abuse, had rights to his social care record under Article 8 of the Human Rights Act (Right to Privacy and Family Life). This included the personal information of other people, as all of the information was central to decisions about

his life. More recently, Durham County Council v Dunn (2012) determined that rights to a fair trial under Article 6 of the Human Rights Act overrode the privacy rights of third parties. Better guidance on applying data protection law in this context is urgently required.

A confused, fragmented legislative and regulatory landscape

Inadequacies in management and access may be the result of an inadequate legislative framework for child social care records. Our research shows that the legislation and regulation which currently govern the creation and management of records in out-of-home care is dispersed and fragmented



Visual minutes from a research meeting in London, with social workers and information managers, © UCL

across more than a dozen Acts and statutes. Overlapping regimes of information legislation (eg, data protection, freedom of information) and social care legislation are both relevant, but rarely comprehensively understood by service providers. We found widespread confusion about basic requirements, such as what records to retain and for how long, and about what was and wasn't 'legal'. The apparent complexity of the landscape appears to lead to increased risk aversion within organisations, and feelings of uncertainty amongst individual workers.

We identified two underlying structural problems. Firstly, that legislation encodes recordkeeping inequalities between children based on their status, expressed through retention periods and access regimes. Secondly, that information rights legislation does not provide sufficient guidance to requesters and practitioners about access to records.

Since the Children Act 1989, children have been assigned a status based on the sort of intervention they receive, eg, whether they are adopted, are in care, or are in receipt of support as a 'child in

need'. Different records are required, and different retention periods applied to those records, governed by separate regulations.

For example, the records of an adopted person must be kept for 100 years from the date of the adoption order, while records of a care-experienced person must be kept for 75 years from the date of birth. Records of children in need are only kept for 25 years from the date of birth, even in instances where their experience is analogous to a care-experienced person. Likewise, the support for records access differs. Whereas records counselling and intermediary services must be provided for adopted people at any age, they are only required for care leavers up to the age of 25. These differences are illogical and unfair, and our research participants have told us they reinforce societal prejudices about their relative value and worth. In many cases retentions legislation has been shaped, *ad hoc*, by uninformed pragmatism that becomes enshrined in law, without due regard to the needs of the individual.

Similarly, guidance on the implementation of GDPR and the Data Protection Act 2018 is currently insufficient to support the unique information needs and rights of people who grew up in out-of-home care. While the law itself is designed to enable access, it is often used in practice to restrict it. For example, risk-averse interpretations of the exemption of 'third-party information' leads to the high levels of redaction already discussed. Our research has shown that staff making decisions about redaction have a relatively low level of responsibility within organisations and are frightened about legal or insurance consequences if they act wrongly. As no guidance or standard for redaction is available in this context, organisations and individuals act as they deem appropriate in each instance. This leads to significant disparity in the extent of redaction, both within and between organisations.

Fulfilling our information rights responsibilities

MIRRA's findings suggest the need for wide-ranging change to recordkeeping cultures and practices in social care. In response, the project has generated a range of resources to support care leavers and practitioners in navigating current challenges.

In the first instance, we have compiled a document of aspirational principles for recordkeeping with care – Principles for Caring Recordkeeping in Child Social Care – which outline how practitioners could better create, manage and provide access to records.

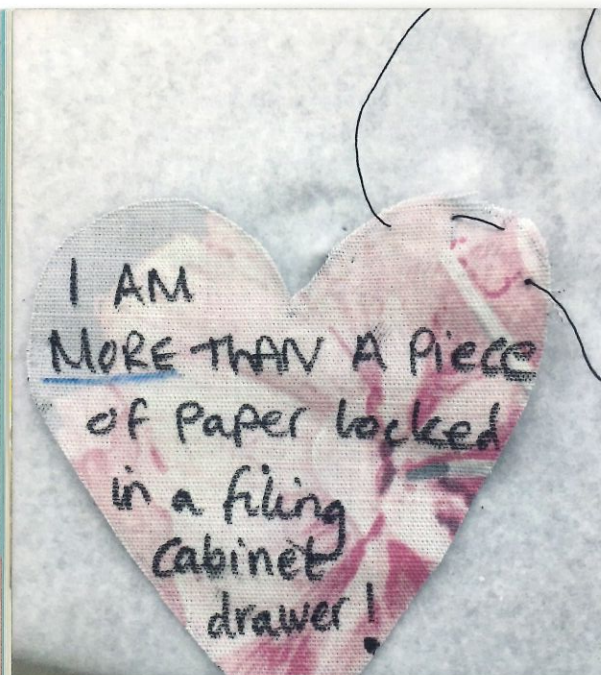
Each principle is expanded in an accompanying toolkit, which sets out how organisations can assess their current practices and work towards meeting care leavers' needs, as well as their information responsibilities. Both are free to download from our project website: <<http://blogs.ucl.ac.uk/mirra>>. We recognise that

some actions will need additional resource and investment, especially if bodies of unprocessed legacy records are involved. We have produced a range of advocacy resources that you can use in making a business case, including a short film with care leavers about why their records are important to them. You can watch the film on YouTube <<https://youtu.be/xs28tczL3yA>>, and download the associated case studies from the Resources area of our website. Those who would like to know more about the research and hear the research team speak can find recordings of sessions from our research symposium in July 2019 on our YouTube channel: <<https://www.youtube.com/channel/UCCziwvm2QblkkBYT1OKIsAw>>.

At the same time, we have been working with policymakers and regulators to produce best practice guidance for recordkeepers. In particular, we are collaborating with the Information Commissioner's Office, Ofsted and the Department for Education, which we hope will ultimately lead to changes in legislation and regulation that reflect the caring principles. Finally, we have created a Web resource for care-experienced people, in partnership with the charity Family Action, which guides care leavers



Collaborative research meeting with access to records and data protection practitioners, © UCL



A care leaver's message to social workers and information managers, MIRRA symposium, © UCL

through each step of the access to records process. This site is called Family Connect and will launch in October 2019. Ultimately, we hope that MIRRA will contribute towards a reconceptualisation of all aspects of recordkeeping as fundamental to caring for children.

You can follow the project's progress on Twitter: @mirraproject.



The MIRRA research team of academics and care leavers, © Isa Jaye

Helpful resources

Hoyle V, Shepherd E., Flinn A., and Lomas E., Child social-care recording and the information rights of care-experienced people: A recordkeeping perspective, *The British Journal of Social Work* 2018; bcy115. <<https://doi.org/10.1093/bjsw/bcy115>>

Feast J. and Jordan L., Access to Information for Adult Care Leavers: A guide for social workers and Access to Records Officers, Coram BAAF, 2016.

The Care Leavers' Association Access to Records: <<http://www.careleavers.com/what-we-do/access-to-records/>>

Setting the Record Straight for the Rights of the Child: <<https://rights-records.it.monash.edu/>>

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Trust and transparency: In search of a catalyst for openness

By Sonya Sherman

When you hear (or read) the word 'openness' perhaps you think about transparency, open government, open data, and Freedom of Information or (FOI).

Openness is made up of three key components and requires interaction among different groups of stakeholders. Accountability and transparency are important building blocks for trust. And trusted relationships are the foundation for meaningful customer or community engagement.

Reliable information plays an important role in all these components.

Accountability

Mechanisms such as FOI require organisations to make information available to the public in response to a request – the so-called "pull" method. This kind of accessibility drives accountability for actions, decisions and performance.

Transparency

In contrast, approaches such as Rights to Information and Open Data aim to also make information available proactively – the "push" method. This can encourage collaboration and delivers transparency. It helps external stakeholders understand how internal processes work, how decisions are made and the impact of policies or services.

Engagement

The third component is the real heart of openness, and our target future state.

Openness is not just about information flowing out from an organisation, but also flowing in. Beyond the push and pull of information, engagement allows the exchange of ideas and knowledge.

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<<https://blogs.ucl.ac.uk/mirra>>

